EUROCIU
EUROPEAN ASSOCIATION OF COCHLEAR IMPLANT USERS a.s.b.l.

DECEMBER 2020
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PRESIDENT'S MESSAGE

Dear friends and members, I am happy you joined us in this last EURO-CIU 2020 newsletter, our 45 newsletter. This year has been tough for everybody, especially for persons with hearing loss. EURO-CIU was supposedly celebrating its 25 anniversary in the European Parliament,

but COVID has changed all our plans. We do not renounce being there, raising the voice of #CochlearImplantUsers in the @EUParliament, we have just postponed it until further notice.

But this year of being inside our homes has helped in a way to raise visibility and awareness about #CochlearImplants. More #CommunicationBarriers have been raised but society has heard our claims and we have been able to expose and sometimes even take down some of these barriers for good. Accessibility online has increased exponentially helping all of us in our daily life.

This year as well has been the "collaborative" year. The first time ever World “Consensus” about #CochlearImplantation in Adults is a motive to celebrate. We need now to fight to make it a reality in all countries. We had a productive time being part of the World Hearing Forum, European Parliament Commissions, collaborating with European Disability Forum, ANEC (European Association of Standardization), etc. as well as other new organizations like CIICA where we defend persons with #HearingLoss and #CochlearImplant rights.

We now deserve to breathe and enjoy our holidays to come back in 2021 to fight ever more to reach the goal of a complete accessible and inclusive society showing our love for #Hearing. Merry Christmas, Hanukkah and Ramadan!

Teresa Amat (President)

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MESSAGE FROM THE EDITOR

Many thanks for all your contributions - it's good to hear from you all. And we are also grateful to the cochlear implant companies for keeping us up to date. We have all experienced a dreadful year, so let's hope and pray that, with the Covid-19 vaccine becoming available, 2021 will be a much better year. Perhaps we may even be able to meet up, to celebrate 25 years of EURO-CIU.

As always, there are a lot of articles and photographs in this edition, so if you find that the photos are downloading slowly, you may wish to click on "View it in your browser" at the top of the Newsletter.

Please feel free to forward this Newsletter to Members of Parliament, Members of the European Parliament, friends, colleagues and members of your own organisations. We are keen to increase the number of people who can read about the benefits of cochlear implantation. Let's get the message across!

The next edition will be due in March, so please let me have your articles and jpg photos by Monday 8 March 2021. Just e-mail them to me at newsletter@eurociu.eu

It just leaves me to wish you all a very Happy Christmas and a contented and peaceful New Year.

Brian Archbold (Editor)

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EURO-CIU GENERAL ASSEMBLY 2020 – ON-LINE

(Images of some of the participants on-line at the General Assembly - apologies to those whose photo isn't shown!)

EURO-CIU GENERAL ASSEMBLY 2020 – ON-LINE from 9:00 to 14:00 h

On 3rd October 2020 between 09:00 and 14:00 h, EURO-CIU General Assembly was held by Zoom, with the presence of 18 countries and 24 Associations, with a quorum of 75%.

At first the cooperation with other international organizations and scientific researchers were presented. On top, the new International Consensus was introduced by Leo De Raeve who is part of the CAPAC, representing EURO-CIU. For the first time ever the global guidelines on

standards of care for adult cochlear implantation have been written by a group of international experts, writing 20 International Consensus Statements that represent the first step toward the development of international guidelines on best practices for cochlear implantation in adults. What came out is that we stressed that knowledge alone is not enough, but we have to work on promotion; and to work on this, we need CI users.

Sue Archbold presented the CIICA – Cochlear Implant International Community of Action, composed of all stakeholders such as Associations from all over the world, representatives of Doctors and CI manufacturers, that had the first meeting in in Geneva where the guidelines on CI where discussed. What came out is that there is a huge need to work together and the consensus is a huge opportunity to work together on specific targets internationally. There is a lack of awareness, of referral particularly with adults, so that a lot of people are not aware of the possibility of having cochlear implants. The messages of users are really powerful. The only chance to success is advocacy. A digital interactive platform will be created as an active place where we can share what we do.

Our President, Teresa Amat, talked about EURO-CIU World Health Organization World Hearing Forum Member Certification – explaining that the World Hearing Forum is part of WHO and it was created to develop activities for making hearing loss more visible. We recommend taking hearing tests – people who suffer from hearing impairment should not suffer from the stigma. Today there are a lot of solutions that can be very effective. Furthermore, one of the projects of WHO WHF is “Make Listening Safe” – to create a world without dangers for hearing. There are several groups: one is working with youth, one is working on listening devices, one group is working on sounds at entertainment venues, another group is working on media, podcast. This group is working with social media. EURO-CIU is working mainly in the young safe listening Ambassadors programmes; Spain is sending this programme to students.

EDF European Disability Forum News were presented and also MOSAICS by Vice President Robert Mandara, a new industrial project for innovation but also the cooperation with European Hearing Health Forum.

Our Scientific Director Leo De Raeve reported that Covid-19 is a SARS disease, and it can have an impact on audio-vestibular system. Some research is focusing on 121 people hospitalized in Manchester and what came out is that 8 of them were reporting tinnitus. 4 or them already had some problems, but they say it became worse. 30% of people who had Covid reported audio-vestibular problems.

Some activities from EURO-CIU member associations were also reported such as Emergency document for use if Cochlear Implant users become hospitalised made by Reinhard Zille from DCIG e V (Germany), a good example of cooperation among European countries, translated in many languages; and also the video campaign for the celebration of CI Day made by Beatrice Cusmai from AGUAV (Italy). Accessible Education by Laia Zamora; Communication masks CE project were also reported by the President of Federación AICE (Spain) Joan Zamora – trying to find an international standardisation of transparent masks for lip reading. We are all working to have a regulation for transparent masks and whoever has news about transparent materials and approvals, even locally, is kindly asked to contact EURO-CIU.

CI situation during Covid. Survey has been reported by Joan Zamora through a questionnaire and 20 responses from European associations were collected. 80% CI surgery stopped in Europe. Control fitting stopped as well as speech therapy. Remote fitting was maintained in a few countries.

EURO-CIU ongoing projects were also reported during GA. CI statistics project will carried on by Leo De Raeve and EURO-CIU 25th anniversary was postponed because the board wanted to hold a conference in the European Parliament, but Pandemic Covid-19 stopped the organization, so we will try to organise this activity in 2021.

EURO-CIU 2021 in Germany was cancelled for the same reason, so new candidates for 2022 are being researched. European Friendship Week was cancelled as well due to the Pandemic.

In 2021 there will be elections for 2nd Vice-President and Secretary. Second Vice-President is now vacant because Ervin Bonecz resigned. Everybody who wishes can submit their name as a candidate.

Some new projects were also presented: Dementia Document like Spend2Save will be sent to be translated. Laia Zamora presented the Spanish project about Bullying and Cyberbullying among students with Cochlear Implants, a study that has been peer-reviewed and will be published in the Oxford journal of Deaf studies and deaf Education.

Our Vice-President Robert Mandara talked about EURO-CIU visibility, asking all the associations to display the EURO-CIU Logo, sending more videos of CI users talking about their CI implant because these videos motivate policy makers and decision makers. Concerning the Newsletter, prepared by Brian Archbold, more articles would be welcomed.

The Financial situation 2019 was presented by Henry Francois, result: one abstained and 35 in agreement. Finally, 100 % agreed with the work of the board in 2019.

Beatrice Cusmai (Secretary)

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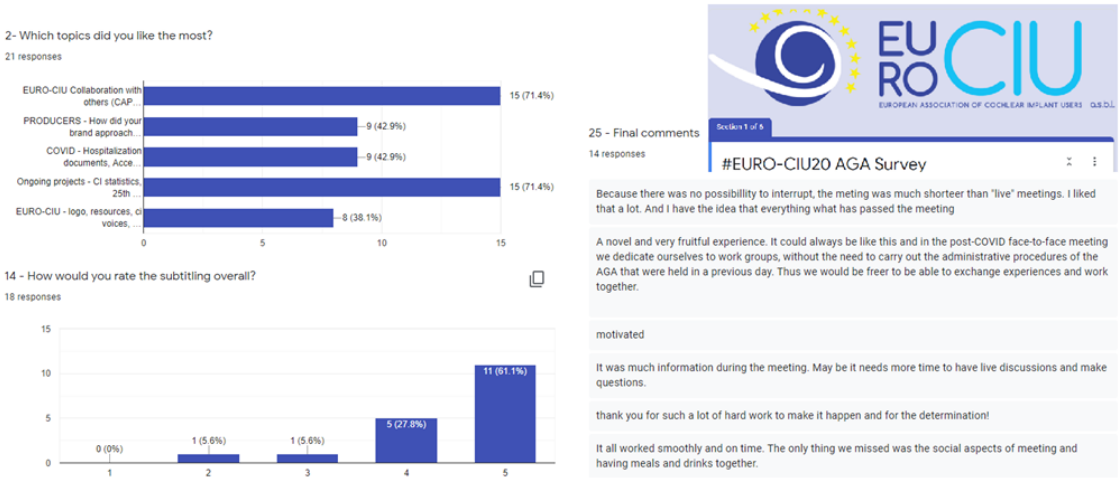
EURO-CIU AGA online 2020 with 95.2% approval among those surveyed



Year after year, the Annual General Assembly is held, in which all the actions that the EURO-CIU Association has carried out are exposed. EURO-CIU is made-up of 33 associations from 25 countries which were represented on October 3rd, 2020 by the 63 attendees at the assembly that was held online due to the global pandemic situation.

Thanks to the live subtitling in various languages (English, Spanish, German, French, Turkish, Polish and Italian), the assembly was accessible to all cochlear implant users who participated (28.6%) and who were able to use this tool to follow the course of the meeting. This accessibility tool has been positively valued by 89% of users.

Throughout the Assembly there were many topics exposed, the attendees through the survey highlighted two of them over the rest. The first consists of the multiple collaborations that EURO-CIU has carried out with other entities (CAPAC, CIICA, WHO, WHF, EDF, MOSAICS), and the second of the topics, all the programs executed and in progress that it carries out with the purpose of giving visibility and relevance to the group of cochlear implants users. "It is good to know the present and future actions", "It is important to show that EURO-CIU exists" are two

of the most outstanding comments left by the surveyed attendees, and which indicates a high degree of satisfaction with the work carried out.

A special mention should be made for the assembly speakers, who were positively valued by all attendees, their choice was a success when we read comments from the survey such as the following: “They seemed so calm throughout the meeting, even on those occasions when the things got a bit complicated "or" All the speakers knew what they were talking about, so it was great and concise."

Also noteworthy are the spoken translation services, which were used by 15 of the people surveyed, evaluating it in whole as good or very good. This accessibility measure allows all associations to be brought closer together without having the language impediment, thus helping to mutually enrich each other among all participants.

Finally, to affirm that the AGA, despite the difficulties presented by COVID-19, has been a success, since 95.2% of the people surveyed have shown their satisfaction with it. It is always nice to be able to meet in person, as some of the participants pointed out, but the agility and convenience of online meetings, with high-quality accessibility, welcomes you to use this modality more frequently in future meetings.

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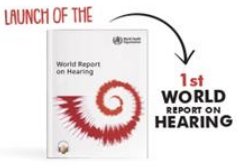
WHO will launch First ever World Hearing Report on World Hearing Day 2021

World Hearing Day
3 March 2021

HEARING CARE FOR ALL

SCREEN • REHABILITATE • COMMUNICATE



eurociu.eu

@eurociu fb.com/eurociu

EURO-CIU is part of the World Hearing Forum, which aims primarily to increase hearing loss visibility and hearing care to society as a whole. Among many other activities, it is organising World Hearing Day on 3 March 2021.

By 2021, WHO will have collected information from all its member countries on good and poor practices related to hearing loss at the international and national levels. This world breaking report will be published on 3 March and is preparing its members, including EURO-CIU, to organize activities and use the report to raise awareness to convince national politicians to improve public health in relation to hearing health.

At the same time, WHO will launch an online marathon called "Hear-A-Thon" that will last 24 hours, in which EURO-CIU has been invited to participate to talk about its school program "Hearing Laboratory" that invites young adolescents to reflect in a friendly and fun way on the practices with which they listen to music, so that their ears are not irreparably damaged.

Follow #WorldHearingDay #HearAThon #HearingWeek #CochlearImplantDay

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EURO-CIU – Number of cochlear implantations in your country in 2017 and 2018

As agreed during last General Assembly of EURO-CIU, we would like to activate our members to fill in the **EURO-CIU survey on the number of cochlear implants in your country in 2017 and 2018**.

Our secretary Beatrice Cusmai has sent 2 Excel-files to all our members, in which they can easily fill in the data on the number of cochlear implanted children and adults in 2017 and 2018.

If you didn't receive this invitation and would like to join us in this survey, please send an email to our Scientific Advisor, Leo De Raeve (leo.de.raeve@onici.be)

We would like to ask you all to deliver him the data-files before 25 December 2020.

In 2016, we were able to collect data from 15 countries, representing more than 100 000 CI recipients in Europe and the results were published in Cochlear Implant International and we hope we can collect more data from 2017 and 2018.

Leo De Raeve, PhD (Scientific Advisor EURO-CIU)

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EURO-CIU is now a member of Hear-it

In 2019 EURO-CIU became a member of Hear-it.org, the non-commercial web site most visited about #HearingLoss in the world with more than 4 million annual visitors and the most comprehensive websites on hearing, hearing loss and tinnitus and how to treat and live with hearing loss or tinnitus.

EURO-CIU participated in the last General Assembly of Hear-it held online this past November and is now member of the board of directors of Hear-it.

Since EURO-CIU joining, Hear-it wanted to show more support on #CochlearImplants and now they have a big section in several languages (English, Spanish, German, French, Portuguese). This 2020 an Italian version of hear-it.org was published - also including the section on implants. You can see it here https://www.hear-it.org/implants . Hear-it is also planning to make some specific videos on CI's in 2021 in cooperation with the implant companies. Hopefully all these initiatives will help increase public awareness of hearing loss and especially about the #CochlearImplant.

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EURO-CIU – Global Guidelines on Standards of Care for Adult Cochlear Implantation

EURO-CIU BRIEFING

GLOBAL GUIDELINES ON STANDARDS OF CARE FOR ADULT COCHLEAR IMPLANTATION

In every country access to cochlear implantation (CI) for adults with severe or profound hearing loss is low. Globally, it is estimated that only one in twenty who could benefit from cochlear implants have one. Most other health treatments have internationally accepted standards of care that inform patients and health care practitioners about when specialist referrals and treatment options should be considered.

This is a gap in the field of adult cochlear implantation that is addressed by a new publication titled "International Consensus Paper on Adult Cochlear Implantation".

They have been developed by an international panel of experts based on examining the latest evidence and consulting with user and advocacy organisations and their goal is to improve access and practice in this proven intervention.

The authors conclude that international guidelines on adult cochlear implantation candidacy are limited, and that guidelines vary from country to country. This leads to both differing levels of access and lack and systematic underuse across the world. The barriers to access they identify include low awareness and understanding of the benefits of cochlear implantation, poor knowledge of surgical candidacy criteria among health care professionals, and a lack of clearly defined care pathways.

There needs to be continued efforts to raise awareness about the benefits of cochlear implants and in many countries update professional guidelines to enable better access to cochlear implants. European CI User organisations are working to raise awareness of the benefits of cochlear implants and advocating for better diagnosis practices, accessible referral pathways, timely access to bi-lateral CI treatment, after care and rehabilitation.

These International Consensus Statements represent the first step toward the development of international guidelines on best practices for cochlear implantation in adults.

The International Consensus Statements for Adult Cochlear Implantation were published in JAMA earlier this year and more information is available on adulthearing.com. The guidelines arising from the Consensus Statements are important in providing an evidence-based approach to establishing cochlear implantation as the standard of care for people with severe or profound hearing loss and illustrating what good practice should be in several key areas.

In order to share the guidelines more widely and support their use in public policy work, we have developed a summary document as a EURO-CIU briefing paper which provides all the 20 statements with their key points for policy work. The document is designed to be used by groups in public policy work, to raise awareness and discussion about adult CI and particularly

the need for early referral and implantation. It is available to download on EURO-CIU website and soon there will also be translations available. It can be given to public and professionals and decision makers alike and promote the conversation you need to have in your health care system to increase access to CI for adults. It can also be used to promote discussions about what is needed next, moving the conversation on. Have a look at www.eurociu.eu!

Brian Lamb, Sue Archbold, Leo De Raeve

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FINLAND - LapCI - Cochlear Implant user now on the Board

My name is Tuulia Harjunmaa. I am a 26-year-old cochlear implant (CI) user, and I work as part of LapCI ry's* Board of Trustees as an expert by experience. My mother is one of LapCI ry's founding members, and I have grown alongside the organisation since its foundation in 1999. When the organisation celebrated its 20th birthday, I figured they would benefit from finally having a board member who had first-hand experience of growing up with cochlear implants.

I am the first and so far the only CI user on LapCI ry's board, as I was also one of the first born-deaf children to receive the implant. This carries a lot of weight, since I know from experience what the world is like for a CI using child without the organisation and its support. I find it extremely important that we are able to prevent the marginalisation of CI using children and teens in the society through our work.

Without LapCI ry, CI using children would fall in between the two worlds: the hearing and the deaf. This is exactly what happened to me before the foundation of LapCI ry: I was only the second born-deaf child to receive the implant in Finland, and so I did not have a peer support network ready and waiting. The experience left me with a serious crisis in identity, and I became deeply depressed quite early due to the lack of support network, among other things. My circle of friends was virtually nonexistent. I have never truly been able to enter the deaf community, and the hearing are not always mindful of my hearing loss. Consequently, I have had no choice but to opt out of social circles. These are issues I am working on to this day. The society often seems to assume that since I have the CI, I am no longer deaf or disabled. Too often this line of thinking leads to significant negligence on the disability rights' front, which is what LapCI ry actively strives to rectify.

Working on the board has given me the front seat view into how the new generations of CI users have developed a strong and unique CI user identity as well as a peer support network. LapCI ry has done a remarkable and vital job in bringing these CI using children and their families together, and ensured that that their rights are being actualised. Thanks to LapCI ry, I am no longer worried for the current generation of CI using children.

Tuulia Harjunmaa, CI user

***** *The Finnish Association of Cochlear Implant Recipient Children*

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GEORGIA - AURES FOUNDATION - The challenges our community has faced

First of all, we would like to thank you again for the excellently organized and interesting AGA. During the meeting, the association members were asked to share the experience of their countries, and we decided to share with ours. The problem we are facing now is not caused by the coronavirus, although the aggravation of the pandemic is affecting its solution.

Although we have effectively dealt with the first wave of the pandemic in terms of the spread of the virus, the consequences of the pandemic were dramatic for our country. Among them, cochlear implant users and service providers have faced numerous challenges: surgeries were postponed, audiological services have been suspended as well as the state program for the rehabilitation of children with cochlear implants. In addition, for reasons independent of the COVID-19 the state program for the supply of cochlear implants has been suspended, the announcement of a tender for the purchase of cochlear implants has been postponed.

We have made great efforts to deal with these results. We were actively advocating for our community. We collaborated with the clinic for the immediate restoration of audiological services, we wrote the state standard of teletherapy for children with a cochlear implant, and we were working with children and families, offering them free consultations. The situation gradually stabilized, but we could not make progress on only one issue - the state program for the supply of cochlear implants for 2020 has not yet started, and there are no signs of this.

We triggered an alarm a few months ago when we saw that the launch of the program was delayed. Since that day, we have maintained close contact with government agencies responsible for implementing the program, parents whose children were expecting cochlear

implants, and service providers. However, all our efforts were in vain. We are told that a reorganization is underway that prevents the program from starting.

Meanwhile, we were hit by a second wave of pandemics, which almost got out of control. Against the background of the current situation, our issue has become secondary for our state.

Meanwhile, time is passing, which is so dear to every child who is waiting for a cochlear implant. Parents are desperate. Some of them even started a campaign to raise funds for the implantation of a child. we decided that there was no time to be inactive.

Our actions did not bring any results, so we decided to expand the issue and launched the “I want to hear the sounds of the world campaign. Give me the opportunity!”. On the official Facebook page of our organization, we published an appeal to the relevant state structures and mentioned the country's leading TV channels and human rights organizations. The appeal is actively shared by our supporters. Although at this stage there was no reaction from the relevant structures and the media (the reason for this is the recent events in the country), we continue to fight for the rights and better future of our children.

The Aures Foundation thank you for providing us with a supportive letter. We are confident that an official letter of support from the association will make our fight more effective.

Our friends from the German organization Deaf Ohr Alive - Rhein-Main sent us dozens of supporting videos on the benefits of cochlear implantation and the importance of timing. We publish these videos on our Facebook page every day. You can see it at these links:

https://www.facebook.com/auresfoundation/videos/3543155649096422/

https://www.facebook.com/auresfoundation/videos/839260286646950/

Teona Gvalia

Development Manager
Social Worker

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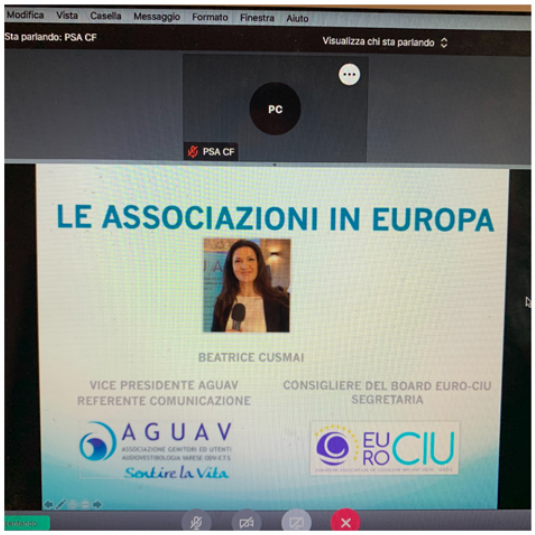
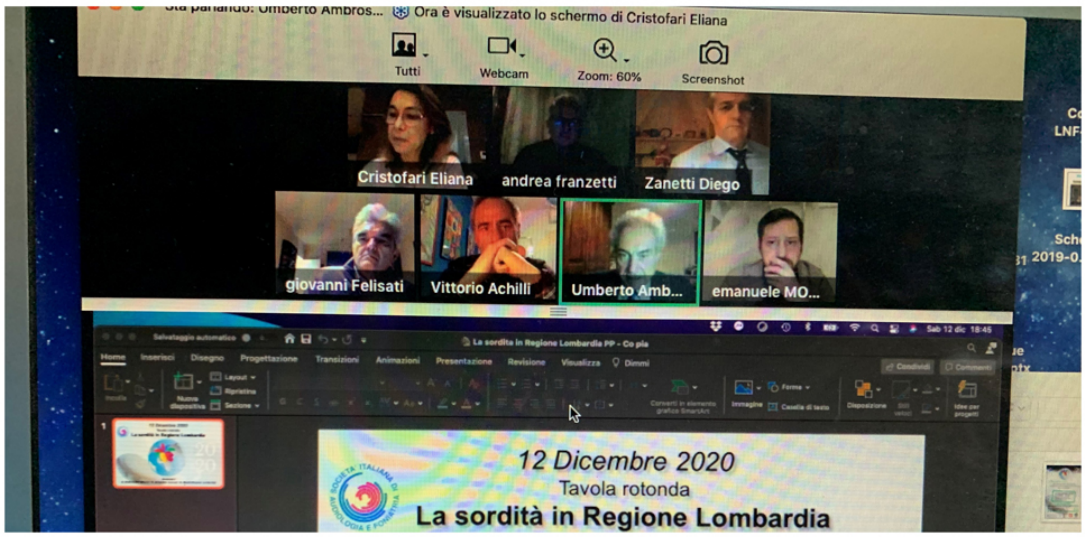
ITALY – AGUAV – THE GOOD 2020 – A global overview on deafness – The past and the next 10 years: “treatment and outcomes of deafness in Italy and Europe”





(Photos: Top left Dr Eliana Cristofari MD, PhD - Varese; Bottom photo includes Dr Emanuele Monti, President of Health Commission of Lombardy)

On December 11th – 12th a huge on-line Congress was organised by AGUAV and FAV, in Italy, to celebrate the 10th Anniversary of the scientific director Doctor Eliana Cristofari who got the leadership of Audiovestibology Department of Varese on 1st December 2010.

10 Years of great success celebrated by a congress with more than 100 Speakers from all over Europe and more than 500 participants. Audiologists, otolaryngologists, audiometry and hearing aids technicians, speech therapists, paediatricians, geriatricians, infant neuropsychiatrists took part at the Congress. Deafness: state of the art and future perspectives, with sessions dedicated to deafness in children, adults, the elderly, surgery and future perspectives were the themes treated during the main session in which doctors from all over Italy and Europe had a speech. International experts spoke such as Erwin Officiers from Belgium, Gerard O'Donoghue (UK), Manuel Manrique (Spain) Thomas Lenarz (Germany) Giorgio Kriafinis (Greece).

Another special session of the Congress was dedicated to Deafness and Inclusion and to Associations because hearing impaired patients with their family members are directly involved in the management of the diagnostic and therapeutic processes. EURO-CIU was presented by our President Teresa Amat who pointed out the fact that EURO-CIU's role is to underline the needs of CI users; Beatrice Cusmai, Vice-President from AGUAV explained how important the

network among European Associations is, and how useful is the synergy and cooperation to reach common goals.

The letter to help Georgia, the Form for hospitalization produced by Germany and translated in many European languages or the AGUAV videos explaining how life can be with CI used to celebrate 2020 CI Day, the close cooperation with WHO are examples of mutual help among European Associations. Furthermore, the importance of Forum and social media has been underlined and a Net of Italian Association for the Overcome of Deafness has been presented during the Congress.

A part of the Webinar was dedicated to the school and home educators as well as the teachers of all schools at all levels, stressing the concept that a person with well-cared for hearing impairment is returned to Society as an active member, trying to change the concept of passive assistance with that of active participation thanks to the tools that allow people to overcome disability.

At the end, a round table was held with the participation of Dr Emanuele Monti, President of Health Commission of Lombardy who underlined how brilliant and clear are the results of Cochlear Implant made by skilled hospitals, so it is important to support them.

Beatrice Cusmai (AGUAV Vice-President)

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THE NETHERLANDS – OPCI project "CI waiting lists and aftercare

(Photo: Hennie Epping)

With its project "CI waiting lists and aftercare", OPCI was nominated for the Impact Prize PGOsupport 2020. With this prize, PGOsupport puts projects and initiatives in the limelight that contribute to the quality of care and / or life with joint efforts from the patient's perspective.

OPCI did not win the award, but is proud of the nomination. In addition, this nomination has yielded something else. Participatiekompas, the knowledge base with information about patient participation, interviewed Hennie Epping, chairman of OPCI, about the project "Waiting lists CI and aftercare".

The interview with Hennie, who clearly explains the waiting list problem, the social and social consequences for those on the waiting lists and the approach to this, can be read here:

Tackle waiting lists #how?

The waiting time of 2 years for a cochlear implant (CI) has been eliminated at 4 of the 8 CI centres since January 2020. How did the Independent Platform Cochlear Implantation (OPCI) do that?
A cochlear implant (CI) is a tool for deaf and severely hard of hearing people with which, in most cases, they are able to hear (again). It is placed during surgery and is therefore very different from hearing aids or other hearing aids.

Socio-psychological problems
People who qualify for a CI desperately need it. The longer they have to wait for it, the greater their social psychological and financial problems sometimes become. Some people become increasingly isolated without an implant, become incapacitated for work, and often end up on social assistance benefits.

Signals from fellow sufferers
"The standard preparation time of 6 months is still manageable, but waiting 2 years before surgery is really unacceptable. That long waiting time was already pretty much the norm in 2016, as we learned from fellow sufferers during our living room meetings," says Hennie Epping, chairman of the Independent Platform Cochlear Implantation (OPCI) and lobbyist in this process. OPCI represents the interests, provides information, and ensures contact with fellow sufferers for people with a cochlear implant and for people who are considering a cochlear implant

From health insurer to the wall
OPCI decided to tackle the long waiting lists. But where do you start? *"We started with health insurers. After all, they are about the money to expand the capacity at the 8 academic CI centres. We raised the problem by letter. The insurers replied that they are not about that. They divide the available money over the university medical centres, and they have to solve it."*

Together with healthcare professionals
"Then we also approached the boards of directors of the 8 academic centres with a letter. Some responded, some did not. An important response came from Nijmegen. The head of the ENT department (Throat-Nose-Ear) there recognized the problem. He had good contact with the CI team and recommended that the letter be sent to the heads of ENT of all other university centres. They may not have been aware of the problem, because although they are responsible for the CI centres, they are somewhat further away from the practice."

To the House of Representatives
"In the meantime, we have contacted the Permanent Parliamentary Committee for Health, Welfare and Sport by e-mail, through one of our people who has access to the SP. The CDA and the PVV invited us for an interview."

OPCI informed the Parliamentary Committee about the problem and the costs. And stated that although a CI costs around € 70,000 up to and including the first rehabilitation, this investment also saves a lot of costs. For example, through less expenditure on psychological care and fewer benefits because fewer people are outside the work process. *"And then you see that it is difficult for departments to see across each other's borders; Public health has nothing to do with Social Affairs."*

Working with healthcare professionals
Meanwhile, all heads of ENT of the university medical centres recognized the problem and supported OPCI. With this information, OPCI again contacted the boards of directors and this led to the decision to draw up an improvement plan on behalf of all CI centres, together with the Nijmegen CI team.

To the Dutch Healthcare Authority
The Dutch Healthcare Authority (NZa) came into the picture in this process. The NZa ensures that approved care is provided in the correct quantity and quality. In the meantime, OPCI had a large file with facts and statements of support that it therefore sent to the NZa in the hope that someone there would pick it up. And that happened.

"We talked to a member of the Nijmegen CI team and a controller. That was very nice, because we brought experience knowledge, medical-technical knowledge and financial knowledge with us. For example, the controller calculated that the lifetime costs of a CB, including aftercare, amount to €1,000 per year, per person. So, the initial costs are high, but it is not too bad for a

lifetime. Moreover, a CI pays for itself. Children with a CI often need less use of special education, can often keep up with school reasonably well and therefore have more opportunities on the labour market. As adults, they often have less to rely on psychological help and benefits."

Plan of action
The NZa gave OPCI a format for a balanced action plan for a solution direction. Consultations were subsequently held with CI-ON, the consultation body of the CI centres, to determine, among other things, the acceptable waiting time. *"We have set it at 6 months. After all, it takes a lot of time on research and preparation from approval to implantation."*

Results
The entire lobbying process took more than 3 years, but the result is satisfactory. *"Without intervention by the NZa, all centres have now made more money available for CI care and 4 of the 8 centres no longer have a waiting list. Financing of aftercare remains an important point of attention. The processor of a CI is replaced every 5 years. In order to reduce the overall costs to some extent, the basic provision has been levelled at all centres. Previously you got certain extras at one centre and not at the other. That is now the same everywhere. Users now pay for nice gadgets themselves."*

Perseverance, relationships and cooperation
What does the long road that OPCI has taken teaches us about the approach to waiting lists in general? *"That it is indeed a long process, because it takes a while before you reach the right organizations. And that you have to have relationships. We had the advantage that we already had a good reputation within the CI centres and were not seen as difficult patients. The collaboration with the heads of ENT plus their controller was also very important to this success. For example, we could never have made that cost / benefit calculation independently. "*

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POLAND - Stowarzyszenie Słyszeć bez Granic (Hear Without Borders Association)

First of all, we would like to thank you very much for the cooperation and help of the entire EURO-CIU community in the difficult issues with which we approached you. Thank you for preparing the letter that we sent to the Patients' Rights Ombudsman and the Ministry of Health, as well as for the numerous opinions on bilateral implantation that continue to come to us, which are a very valuable source of information.

In recent months, we have continued talks with the Ministry of Health. We have also received correspondence in which the Ministry emphasizes three main possibilities of solving our problem of long waiting time (up to a few years) for speech processor upgrade:

- There is continuous work on the Care of Healthcare Services, the purpose of which is to change the conditions for the execution of the guaranteed implantation and replacement of a cochlear prosthesis or implantation/replacement of a multi-canal cochlear prosthesis.
- The National Health Fund is developing a procedure that allows for central purchases.
- The Act on the Medical Fund entered into force, which, inter alia, is to introduce unlimited access to health services for children up to 18 years of age.

Due to the pandemic, we are still waiting for more information related to the implementation of the solutions listed above.

In 2021, we have a lot of plans that, we hope, will be implemented. First of all, we want to resume the series of educational conferences for implant users "The Road to Hearing". If the epidemiological situation does not allow it, we plan to introduce online meetings. Next year, we would like to focus largely on the integration of people with hearing loss and people with

hearing implants. We realize how important is the exchange of experiences between different people, so next year we will focus on extending our reach.

Another important project that we have already started in 2020 and we are planning to continue in 2021, is the establishment of the Hearing Aid Bank. In order to support hearing impaired children, we decided to create the Hearing Aid Bank. When looking for financing, we thought about collecting plastic caps for this purpose. We have decided to combine our statutory goals with raising ecological awareness. Collecting caps brings tangible profits from the sale of the raw material, which translates into the purchase of hearing aids, and at the same time it builds the habit of recycling. The first results exceeded our expectations, and the response from schools and the entire community was enormous. Thanks to this activity, the first children were equipped with borrowed hearing aids.

We have a lot of plans for 2021, and we wish ourselves and all other organizations, that the world situation will allow to bring all of them to life.

Maria Rekowska (President)

https://slyszecbezgranic.pl/

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SPAIN - AICE - International Day of People with Disabilities – 3 of December 2020

Am I a person with a disability or with diverse abilities?

Campaign of the European Youth Parliament and Federación AICE

International Day of People with Disabilities – 3 of December 2020

On December 3rd to celebrate the International Day of People with Disabilities, the Federation of Associations of Cochlear Implants Users of Spain, Federación AICE member of EURO-CIU, joined the European Parliament of Youth Spain to launch a video showing several young people with cochlear implants, from different countries and with different professions that throw us the question: Am I a person with a disability or with diverse abilities? This video makes them visible, puts them at the centre, normalizing their lives, their virtues.

This year, the COVID situation has left people with disabilities isolated and with lack of communication, especially in the case of deaf people #CochlearImplantUsers #ImplanteCoclear, since masks have been a great barrier for communication. Due to all of this, we collaborated to highlight the different capacities in accessible online format with subtitles in Spanish and English to launch the campaign: “LISTEN TO THE DIFFERENCE, IMPLANT THE EQUALITY”. Tell your story and explain your Capacity. Involve all society, since equality, tolerance and respect are everyone's business.

@eypespana www.eype.es

@federacionaice www.implantecoclear.org

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SPAIN - AICE - Federation AICE obtains the first mask with a transparent window with official analyzes in Spain

Ensayo	Especificación (2) (UNE-EN 149:2001+A1:2010)	Resultado
Resistencia a la respiración • Estado de recepción	7.1, 7.2, 7.16	(mbar)
Inhalación a 30 l/min	FFP1 ≤ 0,6 mbar FFP2 ≤ 0,7 mbar FFP3 ≤ 1,0 mbar	0,11 ± 0,08 0,14 ± 0,08 0,11 ± 0,08
Inhalación a 95 l/min	FFP1 ≤ 2,1 mbar FFP2 ≤ 2,4 mbar FFP3 ≤ 3,0 mbar	0,35 ± 0,09 0,45 ± 0,09 0,38 ± 0,09
Exhalación a 160 l/min	≤ 3,0 mbar	
Hacia delante		0,57 ± 0,07 0,75 ± 0,07 0,67 ± 0,07
Verticalmente hacia arriba		0,57 ± 0,07 0,75 ± 0,07 0,67 ± 0,07
Verticalmente hacia abajo		0,57 ± 0,07 0,75 ± 0,07 0,67 ± 0,07
Hacia el lado izquierdo		0,57 ± 0,07 0,75 ± 0,07 0,67 ± 0,07
Hacia el lado derecho		0,57 ± 0,07 0,75 ± 0,07 0,67 ± 0,07
Contenido de CO_2	7.1, 7.2, 7.12 ≤ 1,0 %	(%) 0,29 ± 0,03

This action responds to the need to transmit health and safety with the use of masks without harming the deaf community with communication barriers such as opaque masks or masks with semitransparent fabric that reflect light.

In the time in which we are, where masks are more than necessary to protect our health, many people with hearing loss find in them a communication barrier. For this reason, Federación AICE has worked to promote the use of communicative masks (with transparent windows), making more and more people and entities aware of the importance of their use to facilitate lip reading.

From Universities to Hospitals its use has been normalized to avoid the social exclusion of all people who needs lip reading support to understand their speaker with the distribution the AICE Federation campaign "20,000 masks for 20,000 smiles".

On October 1st, a new study was requested to submit them to laboratory analysis of the UNE-EN 149 standard and the UNE-EN 13274-7 standard. These tests have shown that they pass the breathability and CO2 tests. Previously, their BFE (96.02), Breathability (26.8 Pa / cm2) and Splash Resistance (0 failures out of 32) had been analyzed by AITEX without a window.

Our masks are made of 4 layers of fabric, 2 of TNT and 2 of viscose. The clear coat is acetate. The window is 9 x 5.5 cm + - 0.5 cm which represent approximately 20% of the total surface of the mask.

Currently, the Comunicative Mask+COM are the only masks with a transparent window on the market that have passed analysis by the National Institute for Occupational Safety and Health O.A., M.P. of the Ministry of Labor and Social Economy of Spain that are carried out in the INSST. This represents another step towards the safe elimination of communication barriers and the integration of people with hearing functional diversity, without losing the safety and health protection of the user or the speaker.

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WORLD NEWS - THE LEHNHARDT FOUNDATION - Charity projects under Corona conditions

(Photos: Rafayel, Sophie & Lika)

The Corona crisis is having a profound effect on all areas of life as we are all experiencing.

We at the Lehnhardt Foundation also had to learn that the otherwise not easy handling of charity projects for deaf children who are supposed to receive a hearing implant did not become easier during this time. Moreover, if these affected children coming from non-European countries are to be provided with a CI system in Germany, the task becomes even more complex under these conditions.

Three children from two different countries and cultures, who are looked after by the Lehnhardt Foundation, were supplied with a hearing implant by Prof. Just, head of the ENT department, at the KMG Clinic in Güstrow, Mecklenburg-Western Pomerania, from mid-September to early November.

Rafayel, four years old, and Lika, five years old, both from Armenia, while four-year-old Sophie came from the Kenyan capital Nairobi. Three little personalities, three different fates, but with the common goal of finally being able to hear and learn to speak.

Rafayel
Getting Rafayel and his parents to Germany initially was not easy. Although the issuing of the required visas was relatively quick under the circumstances, flight booking was not easy at all due to the constantly changing travel regulations, which required quick action as soon as the flight restrictions were temporarily lifted. At the same time, this uncertainty had an impact on the organization of the planned surgery. In addition, there was a negative Covid 19 test required in Yerevan 48 hours before departure and an equally negative test upon arrival in Berlin, which then required a subsequent five-day quarantine before a third test at the clinic decided whether the patient would be allowed to enter the clinic with a parent so that the necessary preliminary examinations and the surgery could be carried out. This procedure required additional effort, whereby the duration of the quarantine times and test results had to be constantly coordinated with the responsible health department. Rafayel and his mother fortunately passed all three tests with negative results and on September 29, 2020, Rafayel was successfully supplied with a CI system. The first fitting of the speech processor a few days later also confirmed the success, and the young family was able to start their journey home overjoyed by the result just in time before their visas expired.

Sophie
Sophie's trip with her mother from Nairobi was more difficult to organize. The burden of the many corona patients in Nairobi made it much more difficult to obtain the necessary documents for issuing visas. Safety requirements by the Kenyan authorities and engagement of the specialists involved in the diagnostics proved to be clear hurdles, as did the strict requirements of the German embassy. There were also uncertain flight plans there, which made precise planning impossible both in Nairobi and in the hospital in Güstrow. When Sophie and her mother finally arrived in Germany, both of them went through the health safety tests and passed the quarantine periods as well. The clinic reacted very flexibly thanks to the experience with Rafayel. Fortunately, all test results were negative as well, the surgery date and the other appointments were coordinated accordingly and on October 6th, 2020, Sophie was also successfully supplied with a CI system. When the first fitting took place a week later and Sophie heard her mother's voice for the very first time, all obstacles and problems were forgotten.

Lika
With the experience from these two projects, little Lika from Armenia should actually be provided with a CI system as the third candidate without any problems.

However, it should turn out differently, because in the third decisive Covid 19 test, which should decide the admission to the clinic, mother and daughter both tested positive. The health department involved, thereupon ordered 14 days of quarantine for both of them and the entire surgery plan was canceled. Now the close cooperation with the authority and the observation of all those involved began, how the health of Lika and her mother was developing. An intermediate test showed that Lika now had a negative result, but the mother remained positive. That meant that Lika could be accepted, but her mother could not accompany her into the clinic, an additional stress for the girl and her mother. In addition, the time ran against the approved duration of the visa.

Finally, Mrs. Abrahamyan, the representative of the Lehnhardt Foundation in Armenia who had traveled with them, agreed to accompany little Lika to the operation as the closest confidante. This made it possible to successfully carry out the supply with the system during the approved length of stay and also to carry out the first fitting on November 2, 2020, just one day before the return journey. Everyone was understandably very relieved that in the end everything went well and Lika was able to start her long-awaited journey into the world of hearing and speaking

These three cases make the additional burdens in this crisis clear and show the special requirements for flexibility and good will of all those involved, so that in the end, regardless of all adversities, these deaf children could find the way out of the silence into the colorful variety of sounds.

And we all agreed that the efforts were worth it.

Klaus Gollnick
Board member of the Lehnhardt Foundation

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WORLD NEWS – Cochlear Implant International Community of Action (CIICA)

Look out on International CI Day, February 25 2021!

Our Vision: A world in which awareness of the benefits of CI are well known to those with hearing loss, their families, professionals in the field of hearing loss, the general public and public health decision makers. A world where access to CI and lifelong support is available where appropriate.

Our Goal: to increase the number of people globally who have access to cochlear implants and lifelong aftercare by:

- Raising the international global awareness of the health, social and economic benefits of cochlear implants for those who could benefit from implantation, health care practitioners and wider society.
- Empowering user led advocacy and awareness raising activity to influence governments and health funders to invest in addressing the under provision of CIs and other implantable technologies, related habilitation, after care and upgrades.
- Supporting CI advocates with the tools they need to achieve change.

CIICA, the Cochlear Implant Community of Action, is to be launched on International CI Day, Feb 25th 2021, following the global consultation on advocacy work for CI by Brian Lamb and

Sue Archbold. There was huge support for the development of CIICA: there are many organisations doing great advocacy work as we can see in this newsletter but the consultation revealed a great desire to work together globally, share activities and resources and not to "reinvent wheels". It also revealed the challenges for users and family groups in terms of time and resources and in getting the user and family voice heard in advocacy work. Hence a Community of Action where the growing advocacy work for CI can be heard and shared and magnified: *"give the megaphone to a group of individuals to enact change…. the only chance for success is the advocacy voice."* and to be *"united in our common mission and goal to access to and support for implantation……."*

The Community of Action will provide a trusted space for this - bringing together the growing effective CI advocacy work, large and small, giving space to the voice of users and families to bring about urgently needed change. This is needed even more at the moment with the challenges faced by health care services and CI services during the Pandemic, and the increasing challenges faced by family and user groups in terms of time and resources. People are now acting as consumers of health care and questioning public health decisions – and this includes access to CI. CIICA will enable groups and individuals to inspire each other – as reading the activities in EURO-CIU newsletter does.

We begin the global conversation on CI on International CI day, February 25 2021; thanks to all who are giving it support, enthusiasm and passion!

Brian Lamb, Sue Archbold; sue.archbold@btinternet.com

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WORLD NEWS – IFHOH Undertakes A Cochlear Implant Advocacy Project

When cochlear implants were first introduced almost 40 years ago, there was some skepticism and some opposition. The International Federation of Hard of Hearing People (IFHOH) was on board and clearly stated its support for cochlear implants in a position paper.

Today, the climate is vastly different as cochlear implants have been recognized in most quarters as a proven technology that improves the lives of its recipients. Yet, there is still a lack of understanding of its benefits and a lack of uptake for the procedure. Many countries have a state-subsidized funding program but many of these programs only fund one cochlear implant, even if a person requires two of them, and most have long waiting lists. Sadly, there are some countries that have no funding or programs for cochlear implants.

IFHOH has embarked on an advocacy campaign to raise awareness of cochlear implants, and to this end held a webinar on October 15, 2020 in which several speakers addressed the topic. Information about the recently released International Consensus Paper on CI Treatment for Adult Hearing Loss was also shared.

Feedback from the participants of the forgoing event was that more webinars should be offered. In response, plans are underway to hold a January event. Details will be available on

the IFHOH website of www.ifhoh.org in early January.

IFHOH is also undertaking a revision of its policy paper, recognizing that it is time for a more substantial update than the one done a decade ago. What will not change is IFHOH's continuing and on-going support for cochlear implants. So many of our members have personally known individuals for whom the procedure has had a huge, and positive, impact on their lives.

The International Federation of Hard of Hearing People (IFHOH) was established in 1977 as an international, non-governmental organization, registered in Germany. IFHOH represents the interests of more than 466 million hard of hearing people worldwide. This includes late deafened adults, cochlear implant users, and people who experience Tinnitus, Meniere's disease, Hyperacusis and auditory processing disorders.

IFHOH has over 40 national member organizations from most regions of the world. IFHOH, the European Federation of Hard of Hearing People (EFHOH) and the Asia Pacific Federation of the Hard of Hearing and Deafened (APFHD), work to promote greater understanding of hearing loss issues and to improve access for hard of hearing people. IFHOH has special consultative status with the United Nations Economic and Social Council (ECOSOC), affiliation with the World Health Organization, and membership in the International Disability Alliance. For more information go to IFHOH's website: www.ifhoh.org

Dr. Ruth Warick
President, IFHOH
president@ifhoh.org

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WORLD NEWS - AUSTRIA - Usher News & Highlights 2020/2021

(Photos: USH logo; and Dominique's daughter with family member Winterdream's Nanook - guide dog retired - partner in crime!)

Have a merry and safe Christmas time and a happy new year, may it be a good one after a difficult one! I am delighted to provide you with information relevant to you during the COVID-19 pandemic and with an update of USH related events in 2020 and 2021.

Precautions for people living with vision and/or hearing loss due to Usher Syndrome during the COVID-19 pandemic

For family members and people living in the same household
BEFORE and AFTER each physical contact/interaction/communication:

- wash your hands 20 seconds following the instructions of the World Health Organisation WHO with liquid soap or use alcoholic hand sanitizer

For people not living in the same household such as personal assistants or caretakers and interpreters (sign language, tactile language, finger alphabet)
BEFORE each contact/interaction all should:

- wear face masks (disposable or self-made/washable, preferably clear masks)
- wash hands or use hand sanitizer according to WHO recommendations
- disposable or washable cotton gloves recommended for tactile communication

AFTER each contact/interaction:

- dispose masks and gloves in household waste or
- wash cotton masks and gloves
- use hand sanitizer or wash hands with liquid soap

In public areas:

- leave home only in accordance with your national containment directives
- never touch your face (mouth, nose, eyes) to avoid infection
- wash hands or use hand sanitizer after each contact with surfaces or packaging material (plastic, metal, cardboard, paper) on public transports, in taxis or when shopping daily needs
- wear (clear) masks and gloves (disposable or washable)
- use disposable tissue or sneeze into elbow to protect others

For medical consultations:

- always contact your doctor or healthcare provider by phone or email before any consultation
- see health care professionals or go to hospital in case of emergency (e.g., retinal detachment and exams and treatments crucial to prevent vision loss are defined as urgent by ophthalmologists)
- evaluate if (re-)scheduled assessments and follow-ups should be postponed, can take place with additional precautions or if you can use telemedicine (online or phone consultations) instead
- apply additional precautions as described above
- avoid touching door handles etc or use disinfectant tissues for surfaces

In case of hospitalization and/or treatment due to COVID-19:

- always inform healthcare providers of your condition, esp. your retinal condition
- all treatments have to be strictly prescribed by healthcare professionals only and to be agreed with your eye expert (hydroxychloroquine or chloroquine use contra-indicated with retinal or some neuroophthalmological/mitochondrial conditions)
- no self-medication! (hydroxychloroquine or chloroquine can be harmful to the retina and toxic if associated to specific conditions such as heart problems)

As for the upcoming **COVID-19 vaccines** check out with your healthcare providers if you as a person at higher risk to catch the disease and if your family members/caretakers can be prioritized.

The European Reference Network for Rare Eye Diseases (ERN Eye) have put together some useful information (patients' FAQs related to COVID-19) here:

https://www.ern-eye.eu/update

ERN Eye also provides useful educational videos to raise awareness about how to welcome deaf people or people with hearing and/or vision impairment in a hospital
https://www.facebook.com/1160371694106929/videos/454554772174258
https://www.facebook.com/watch/?v=120487759335633

If you are interested in multicentric clinical trials and natural history studies for Usher Syndrome within ERN Eye see https://www.ern-eye.eu/clinical-research/clinical-trials-by-disease

For more international clinical trials and natural history studies worldwide see https://www.clinicaltrials.gov/

Clinical trials for Inherited Retinal Dystrophies (IRDs) including Usher Syndrome require patients to have a confirmed diagnosis through **genetic testing** to be included in the trials.

I hope you enjoyed the news and information!

If you wish to receive this information in an alternative format or language, please send an email to usher-syndrome@gmx.at

To make sure not to miss out any important news about USH events, resource files, as well as research, clinical trials and surveys subscribe by sending an email to usher-syndrome@gmx.at.

Dissemination of this information to your interested network is highly welcome.

Information disseminated is for information purposes only. Readers must discuss any intervention with their Eye and ENT experts.

Dominique Sturz, Patient Advocate Usher Syndrome & Rare Diseases, Usher Initiative Austria

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WORLD NEWS - AUSTRIA - "EXCELLENCE dedicated to HEARING IMPLANTS"

The HEARRING Group is an independent network of world leading experts and centers concerned with all aspects of hearing restoration and implantable hearing devices. Through being comprehensive, co-active, innovative and educational they are committed to making progress every day. Detailed information on the HEARRING clinics, their goals, and members can be found on the HEARRING website (https://www.hearring.com/).

HEARRING & COVID 19

In June 2020, the HEARRING Group conducted a survey to better understand the challenges faced by the clinics in their daily routine due to COVID-19.

The survey provides an insight into the impact of COVID-19 on the audiological practices and into the preventive measures taken in different clinical setups in different countries.

The main COVID-19-related challenges are the limited offer of audiological services, as most of these still require an in-person visit, and missing and delayed testing and/or treatment to the detriment of patients, especially children and patients requiring troubleshooting. The level of challenge varies according to the type of clinical setup (i.e. big hospital vs. private practice in a medical center).

Most clinics surveyed already had preventative measures in place by June 2020. These measures included hand disinfection, social distancing in waiting areas, mask provision to patients at clinics, temperature measurement at the facility on arrival, scrutiny of COVID-19 related history at the appointment request, COVID-19 screening questionnaires on arrival, and PCR testing before in-person visits. As the SARS-Cov-2 virus might be a daily companion for a long time, clear measures need to be determined and standardized to ensure safety for both patients and audiologists. For this, clinics need to share their experiences through discussions and surveys to facilitate the establishment of a best practice for the provision of safe audiological services in all different clinical setups.

Prof Dr Wolf-Dieter Baumgartner

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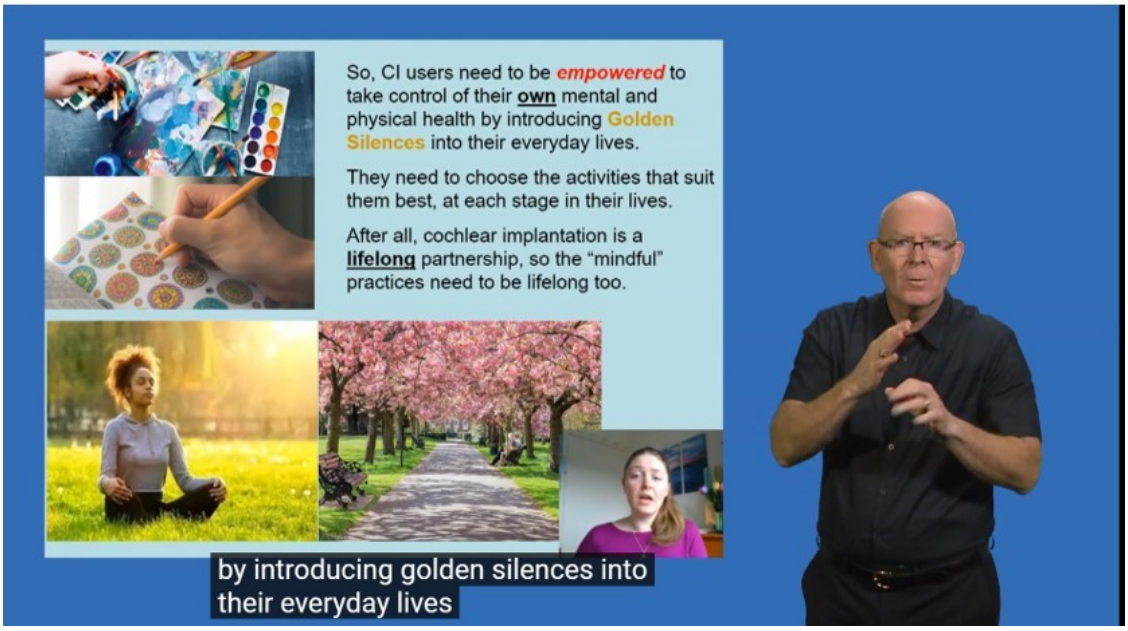
WORLD NEWS - UK - BATOD update



Publications:

BATOD has been active in the support to members and colleagues working with deaf children, young people and families.
The UK Assistive Listening Technology Working Group and BATOD have published this document which summarises care and maintenance of equipment, including radio aids, but signposts to manufacturers' and other websites for the latest information.

Click here: Cleaning hearing devices and radio aids – supporting health and safety during Covid-19 v5

Webinar recordings:

The BATOD National Conference Committee organised a successful webinar in November. The presentation by Dr Helen Willis on 'The future for the cyborg generations: Helping CI users live in harmony with their technology' received excellent feedback. The accessible version of

the webinar recording went live this week and can be accessed here: https://youtu.be/IUlL2LPfoUg

The BATOD Midlands Committee was equally busy in this year of uncertainty planning a very popular webinar to celebrate the upcoming 40th anniversary of the first paediatric cochlear implant, in a unique collaboration between BATOD Midlands, the University of Birmingham and the Economic and Social Research Council (ESRC). Over 200 guests attended a Friday evening webinar tracing the past, present and future of cochlear implants in children. Of special mention was the part that people in the Midlands region of the UK had played in this story. Starting with an inspiring film by the House Ear Institute in California, and with guest speakers including Dr Sue Archbold and Dr Emmanouela Terlektsi, questions were posed such as: 'What have we learnt so far?', 'What are the benefits and issues?' and most importantly 'What does the future hold?'. The narrative was illustrated with videos of deaf children and their families in the Midlands region, reflecting on what the device had meant for them.

Although it is clear that there are many unresolved questions and issues, overall, the benefits are evident, and so we raised our glasses to the toast 'Here's to the next forty years!'. The recording of this webinar is now available via https://www.youtube.com/watch?v=1UCQEsEJexM&list=PL5TjiPIpilP9js50AOPVL8oumy4A7Ov_1&index=14.

A copy of Dr Emmanouela Terlektsi's presentation is also available via https://www.batod.org.uk/wp-content/uploads/2020/12/ESRC_13.11.2020_FINAL.pdf.

Teresa Quail
Co-National Executive Officer and Magazine Editor
British Association of Teachers of the Deaf (BATOD)

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WORLD NEWS - UK - Auditory Verbal UK

(Photos: clockwise from top - Oliver, Jodie and dog Ruby, and Lily)

In November, Auditory Verbal UK published a new Position Paper which sets out the latest evidence on Auditory Verbal practice in the UK and around the world. The paper makes an important contribution to the global effort to influence Governments and those responsible for services to invest in family-centred early intervention for children with cochlear implants.

On launching the paper, AVUK Chief Executive Anita Grover said:

"Far too many children in the UK and around the world are missing out on effective support in the critical early years of their lives. Whether a child uses spoken language, sign language or both, families need support right from the start. We call on those Governments to make the necessary investment that will enable deaf children to have the same opportunities in life as their hearing peers."

Senior Auditory Verbal therapist and Research Co-ordinator, Sarah Hogan said:

"We are now twenty years in to our 21st century. Our 2020 Position Paper details the improving outcomes for children with hearing loss whose families follow the Auditory Verbal approach. The Auditory Verbal approach is used widely across the globe with easy access for families in some countries and with government funding for this early intervention in other countries. Our Position Paper brings together the new areas of focus in Auditory Verbal intervention and highlights research from the growing evidence base for the effectiveness of this early intervention programme"

The end of 2020 not only marks the end of a very difficult year for everyone due to the global pandemic, but for Auditory Verbal UK, it marks the 18th Birthday of our charity, founded by Jacqueline Stokes who was the first Auditory Verbal (AV) therapist in the UK.

Jacqueline began providing Auditory Verbal therapy to families of children with permanent hearing loss in the UK in 1999 and then in December 2002, established The Auditory Verbal Centre. Today, as the organisation 'comes of age' AVUK is providing an Auditory Verbal programme to families right across the UK at its two centres and through telepractice. It is training professionals in Auditory Verbal practice across the UK, Europe, Middle East and South Africa through its internationally accredited programme. Its bursary scheme for families and professionals wishing to train, is increasing access for all.

Since the start of the global pandemic, AVUK has supported families and professionals on its programmes through telepractice. The feedback has been overwhelmingly positive and a hybrid model of telepractice and in-centre services will be at the heart of AVUK's approach in 2021 and beyond. You can find out the latest courses for professionals here or sign up for our newsletter to keep up to date.

Despite the challenges of the pandemic, we also hosted our fifth annual Loud Shirt Day at the end of October and for the first time the event was on the same day as other listening and spoken language organisations in the First Voice network in Australia and New Zealand. We are grateful to everyone who took part in the UK and around the world. You can read more here.

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WORLD NEWS - USA - American Cochlear Implant Alliance - CI CAN (Cochlear Implant Consumer Advocacy Network)

ACI ALLIANCE®
AMERICAN COCHLEAR IMPLANT ALLIANCE

CI CAN
COCHLEAR IMPLANT CONSUMER ADVOCACY NETWORK

Public policy that bears upon access to cochlear implants is a critical element of the mission of ACI Alliance. By helping policymakers understand what matters to people and to the process of providing quality clinical care, your personal stories of living with significant hearing loss yourself or with a family member or friend is critical to our success.

CI CAN is a new initiative designed to amplify our ongoing efforts with grassroots advocacy. Anyone who has or needs a cochlear implant or supports others may join our network. ACI Alliance staff and volunteers provide training and guidance. There is no cost to join or participate. Training is conducted via email or live virtual/visual events with captioning. Join our network and help us make a difference. Join us!!

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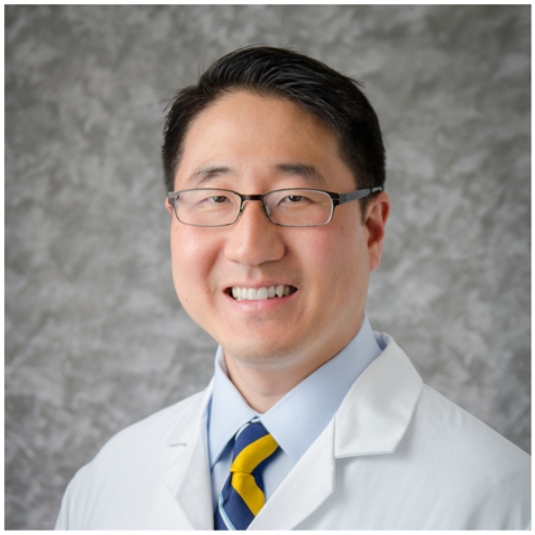
WORLD NEWS - USA - American Cochlear Implant Alliance - “The Development of a Cloud-Based System for Remote Cochlear Implant Programming and Speech Perception Testing.”



(Photos: Colleen Polite & Charles Limb)

American Cochlear Implant Alliance (ACI Alliance) Awards Telehealth Innovation Grant to University of California San Francisco Medical Center

ACI Alliance is pleased to announce the award of a one-time grant to the Douglas Grant Cochlear Implant Center at University of California San Francisco Medical Center (UCFS) to study “The Development of a Cloud-Based System for Remote Cochlear Implant Programming and Speech Perception Testing.”

The COVID-19 pandemic has prompted the need for transformative and innovative approaches to providing care to cochlear implant (CI) patients and candidates. This grant was awarded to support data collection and research that may be used to justify financial reimbursement of telehealth for CI-related services by the Centers for Medicare and Medicaid Services (CMS) and other insurers. ACI Alliance encouraged proposals which involved innovative team-based approaches incorporating elements of diagnosis, programming and/or rehabilitation. The award is intended to facilitate the grant recipient's preparation of a more comprehensive individualized research plan suitable for submission to the National Institutes of Health (NIH) or comparable funding agency. ACI Alliance reviewed each proposal thoroughly using a robust NIH-style review.

The grant was awarded to Colleen Polite AuD, Senior Audiologist and Assistant Director of the Douglas Grant Cochlear Implant Center at University of California San Francisco Medical Center (serving as Principal Investigator for the grant) and Charles Limb MD, also of UCSF. The proposed research focuses on a model of remote programming and CI speech perception testing. The televisit would take place in the patient's home with the vision of ultimately creating a cloud-based system for remote cochlear implant programming and speech perception testing.

Donna Sorkin, Executive Director of the ACI Alliance, notes that "ACI Alliance advocacy during COVID has emphasized the need for CI telehealth insurance coverage — both now and during the post pandemic timeframe. We supported several legislative proposals including the Knowing the Efficiency and Efficacy of Permanent (KEEP) Telehealth Options Act of 2020, a bipartisan bill introduced in the House of Representatives." *(Please see next article)*

Dr. Limb and Colleen Polite stated they are "extremely excited to develop a cloud-based remote programming protocol for cochlear implant patients and grateful for the support from the ACI

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WORLD NEWS - USA - American Cochlear Implant Alliance supports Bipartisan Bill to Document Cost Effectiveness of Telehealth

Rep. Axne Introduces Bipartisan Bill to Catalog Quality and Effectiveness of Telehealth Programs

Rep. Cindy Axne (IA-03) and Rep. Troy Balderson (OH-12) introduced new bipartisan legislation that would require a formal documentation of the costs, efficiency, and quality of telehealth programs in order to catalog their effectiveness and support the continuation and improvement of telemedicine. These studies will show that telehealth programs are a successful model of health care and should be utilized more in the future.

The coronavirus (COVID-19) public health crisis has shifted many treatments to telehealth, allowing for services like primary care check-ups, physical therapy sessions, and mental health appointments to continue without unnecessary risk to the patient. In particular, policy changes during the COVID-19 pandemic reduced barriers to telehealth access for mental health access under Medicare and Medicaid.

The Knowing the Efficiency and Efficacy of Permanent (KEEP) Telehealth Options Act of 2020 would commission studies by the Department of Health and Human Services (HHS) and the Government Accountability Office (GAO) to gather information on telehealth use during COVID-19 in order to support making telehealth options and adjusted reimbursement rates permanent.

Read entire PDF here.

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RELATED CONGRESS - IFOS 2022

IFOS 2022 VANCOUVER
June 18-22, 2022
ENT WORLD CONGRESS

The unprecedented events over the past nine months have challenged all of us, including the committee organizing IFOS 2021 Vancouver. The local organizing committee, IFOS Board and the Canadian Society of Otolaryngology-Head and Neck Surgery have been assessing the ongoing global pandemic and its potential impact on you as attendees, your families, and your communities.

While we look forward to showcasing Vancouver, we have made the difficult decision to postpone IFOS 2021 Vancouver. It will now be IFOS 2022 Vancouver from June 18-22, 2022.

Attendees can expect the same great educational and social meeting in 2022. More information can be obtained from our website (https://www.ifos2021vancouver.com) .

As 2020 comes to a close, we wanted to take the time to send out our heartfelt gratitude to the IFOS community for all your efforts this past year. It has been a difficult year for many. Some of us have lost loved ones; some of us have lost colleagues. However, the mutual support and comradery that each has shown others have revealed a side of our humanity that should be acknowledged, respected, and admired.

The IFOS Vancouver 2022 Committee is looking forward to when we will once again see each other in person and not through the lens of a digital world, to opportunities to share knowledge and stories and laughter with each of you, our colleagues, whether in Vancouver on June 18-22, 2022, or even sooner should the world open once more.

Wishing you all the best in 2021.

Happy New Year to you and your families!

On behalf of the Organizing Committee and the Canadian Society of Otolaryngology-Head and Neck Surgery

Brian Westerberg
IFOS 2022 President

Frederick Kozak
IFOS 2022 Vice President

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RELATED CONGRESSES - Update of USHER related events 2020 and 2021

International Usher info Symposium scheduled for 26-27 June 2020 in Paris, France, is postponed

Details will be announced as soon as possible, we will keep you updated.
Scientific & Patient Symposium organised by Fondation Pour l'Audition and Fondation Voir et Entendre in the framework of the LIGHT4DEAF project dedicated to Usher syndrome.
http://pro.usherinfo.fr/2020-international-usher-info-scientific-symposium/

USH Connections Conference - Usher Syndrome Coalition scheduled 10-11 July 2020 for Austin, TX, United States, went online

This year's USH2020 Connections Conference organised by the US based Usher Syndrome Coalition was a virtual event from 6-11 July, the in-person event is postponed to 9-10 July 2021 at the same venue. https://www.usher-syndrome.org/ush2020.html

USH Camp Europe 2021/22

The format (virtual and/or in-person) of a European USH Camp for teenagers and young adults, following the model of the European CI Friendship Week, is being discussed with our collaborating partners, details expected soon.

Relevant Rare (Eye) Disease related events

ERN Eye General Annual Spring Meeting & Autumn Meeting went online

The General Annual Meeting of the European Reference Network for Rare Eye diseases ERN Eye was a virtual event in March. The October Meeting also had to go online and was dedicated to the integration of the new affiliated partners and parallel sessions in the disease area specific and the transversal workgroups.

https://www.ern-eye.eu/news/calendar/calendar-specific/agenda-ern-specific-ern-events/ern-eye-general-annual-meeting-vilnius-postponed-to-14th-16th-october-2020

A Scientific Meeting with news about European research projects and projects done in collaboration with international partners will be held 2021. An update about new full ERN Eye members and should be available by June 2021.

RIWC 2020 - 21st Retina International World Congress scheduled for 4-6 June 2020 in Reykjavík, Iceland, online

This year's RIWC consisted of several virtual events, the in-person event is postponed to 2022. The Nordic Ophthalmology Congress is also postponed to 2022 at the same venue. During the events we are planning to hold an **Usher Syndrome satellite meeting**.

European Conference on Rare Diseases 15-16 May 2020 (planned to be held in Stockholm) in online format

ECRD2020 was the globe's largest, patient-led rare disease event with 1300+ attendees and 100+ speakers. For the first time 100% online and with reduced registration rates it was an unrivalled opportunity to learn, network and exchange. Plenary sessions were broadcasted live in English, French and German. Live captions and sign language in English were available for accessibility.
https://www.rare-diseases.eu/programme/

Dominique Sturz, Patient Advocate Usher Syndrome & Rare Diseases, Usher Initiative Austria

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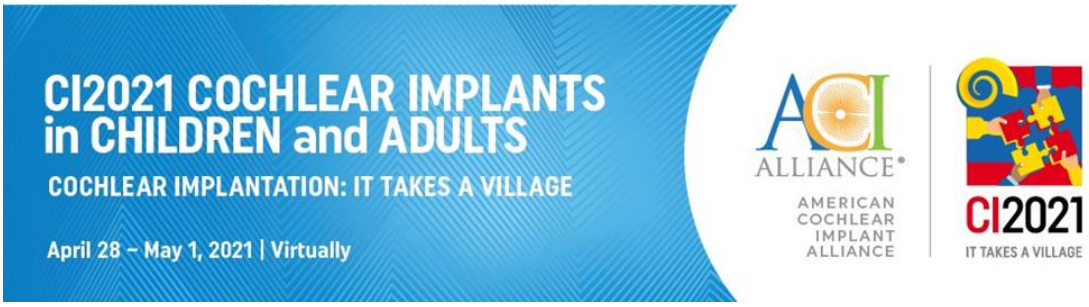
RELATED CONGRESS - USA - American Cochlear Implant Alliance - CI2021: Cochlear Implants In Children And Adults



The CI2021 conference will foster dissemination of multi-disciplinary scientific information applicable to audiologists, physicians, speech pathologists, scientists, engineers, educators, students, advocates and others involved in cochlear implantation. The conference will provide attendees with opportunities to explore current and emerging topics for CI patients across the lifespan.

Anticipated topics for the CI2021 meeting include the use of telehealth for CI patients, the impact of a team approach, management of special needs populations, cognition and effect on CI outcomes, advances in CI technology and surgical techniques, roles of therapy and family engagement, the role of vestibular assessment in the CI process and more! Click here to learn more about registration and our program.

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ADVANCED BIONICS - AB wins Top Innovator Award

Advanced Bionics is very proud to have been awarded with the **Innovations-Award 2020/2021** from the Swiss Institute for Quality Tests.

"Patents enhance the economies power, pave the way to progress and in this way, shape the future" – The Swiss institute for Quality Tests.

This award reflects Advanced Bionics commitment to innovation as it is awarded based on the number of patents as well as the qualitative factor of frequency of citations. Companies awarded with the innovation award 2020/21 demonstrated an outstanding score as well as standing out as the best in their segment.

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ADVANCED BIONICS - AB Blog - Your Cochlear Implant Resource

Did you hear? The Advanced Bionics Blog is live. CI experts, CI recipients, or parents of children with Cis are here to share Powerful Stories and Information on cochlear implants and hearing loss, about their hearing journey and other helpful articles on hearing loss and cochlear implant technology.

We hope this blog will become a source of information and inspiration as you progress in your own journey to better hearing, or if you have a dear one who is about to embark in this same journey.

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COCHLEAR – My first days with the Kanso® 2 Sound Processor

By Sylwia Swiston. Bilateral Cochlear Nucleus CI500 recipient and Account Manager with Cochlear Germany.

Five years ago, two dark brown Nucleus 6 sound processors opened up my world of hearing and endless possibilities. Even so, like many CI recipients, I wished I could connect to that world of clear sound more discreetly. In my wildest dreams back then, I did not imagine that one day I would be using advanced hearing technology in a small, simple and comfortable off-the-ear design that – in my case – is practically invisible.

Swapping my BTE sound processors for two new Kanso 2 Sound Processors turned out to fulfill all my wishes and has exceeded my expectations. Here's why I fell in love with Kanso 2 on day one:

1) I find it comfortable and easy to use

Kanso 2 is so small and light that I easily forget that I have it on my head. Even with my hair up, the processor remains practically invisible and it is a great feeling to have nothing behind my ears. One of the most convenient things is that there are absolutely no buttons or switches to fiddle with.

2) Direct connectivity:

One of the features which I could not live without anymore is the direct streaming. Phone calls were a nightmare before I got my CIs and now I enjoy streaming calls, music and entertainment straight to my sound processors without additional devices or cables. I am fascinated by the sound quality and the fact that I don't need extra accessories to experience the joy of streaming.

3) Wirelessly charging and drying at the same time makes it easy

With the new charge and drying unit, I just put my sound processors in the box and close the lid. No cables, connectors or dry-briks needed. The built-in rechargeable battery then keeps me going the whole day.

4) Waterproof security

I don't worry about water-based activities anymore. Kanso 2 has the highest dust and water resistance rating. I work out and enjoy rainy days without a second thought. And with the Aqua+ I can even swim in the pool, lake or sea ***(1)***.

I shared my excitement when unboxing the Kanso 2 in this video on YouTube (in German, with English subtitles), and now I'm very much looking forward to new adventures with my two Kanso 2!

Views expressed are those of the individual. Consult your health professional to determine if you are a candidate for Cochlear technology.

Please seek advice from your health professional about treatments for hearing loss. Outcomes may vary, and your health professional will advise you about the factors which could affect your outcome. Always read the instructions for use. Not all products are available in all countries. Please contact your local Cochlear representative for product information.

(1) *The Kanso 2 Sound Processor is dust and water resistant to level of IP68 of the International Standard IEC60529 and can be continuously submerged under water to a depth of up to 1 metre for up to 1 hour. The Kanso 2 Sound Processor with Aqua+ is dust and water resistant to level of IP68 of the International Standard IEC60529 and can be continuously*

submerged under water to a depth of up to 3 metres for up to 2 hours. Refer to the relevant User Guide for more information.

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COCHLEAR – Giving others the support they need

Jacob Johanen, bimodal CI user from Sweden shares his excitement about being a Cochlear Volunteer.

My cochlear implant has changed my life for the better in every way. I feel a responsibility to share what it means because I know that many people out there, living with severe hearing loss and all that it entails, could have a completely different situation in life.

The Cochlear Volunteer Programme has contributed a lot to my confidence. At volunteer meetings we receive training in how a volunteer may act both in one-on-one meetings and speaking in groups, meeting with other volunteers, sharing ideas and helping each other. As a volunteer, I have contributed by sharing knowledge and awareness with the general public and to potential CI-users. Most of all, I describe what a difference the cochlear implant makes in my life; for example, as I do in this video. (In Swedish, with English subtitles). This brings me a lot joy. Because of my positive experience of having a Cochlear Implant, being able to share with others means that hopefully they can have a similar experience.

Every time I meet someone who has a severe hearing loss, I am reminded of what it was like for me when my hearing was so bad that it no longer helped even to wear a hearing aid. All the difficulties and limitations it entailed, how a big part of my life and my quality of life was badly affected. I naturally tend to resist all kinds of help, and I remember how difficult it was to accept the support available to help me hear better. With these experiences in mind, I therefore try to motivate and share what difference a CI can make for these people.

When someone is interested, I am very happy to be able to support them in the journey towards obtaining a CI. As it gets better for most people, it feels very rewarding to have supported someone to a better quality of life.

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MED-EL – The new RONDO 3 audio processor combines easy use with smart technologies

Following its philosophy to provide custom-fit solutions matching each person's individual needs, MED-EL has launched the RONDO 3 Audio Processor, the latest product innovation. With **wireless streaming**, **wireless charging** and **Adaptive Intelligence** RONDO 3 provides all day hearing. Being compatible with nearly any brand and type of hearing aid, it is the simple yet smart choice for a more natural sound quality and more joyful hearing every day.

The **enhanced noise reduction features** reduce distracting background noises to further improve the understanding of speech. The Automatic Sound Management 3.0 and Adaptive Intelligence technology automatically **adapt to any sound environment**. In addition, RONDO 3 **allows for richer music experience** with its FineHearing technology. Even swimming or diving is made simple with WaterWear: the reusable and fully waterproof covers keep the audio processor safe and dry.

The refined design of RONDO 3 provides even more comfort for everyone being light, extremely slim and barely visible on the head. In addition, RONDO 3 offers plenty of choices to personalize with over 30 cover designs – from natural to colorful and expressive.

CI user Tom (UK) tells about the importance of the right audio processor: *"From my experience, people with a severe hearing loss often fear that an implant solution will not measure up to the natural hearing they once experienced. It is the steady improvement and technological innovation of devices such as audio processors that truly make a difference for people's lives! What a joy to hear your child's voice again loud and clear! The only downside of the new*

RONDO 3 I could detect is that I can tell the lawnmower needs a service. While it was just loud noise before, I can now tell it is not running right!"

Learn more here.

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MED-EL – First surgeries ever in Europe with a totally implantable cochlear implant

(Photo: Prof. Dr. Philippe Lefèbvre)

On 24 September, the first person in Europe received a novel totally implantable cochlear implant (TICI). It was implanted by Prof. Dr. Philippe Lefèbvre, head of the ENT Department of the CHU of Liège and Professor at the University of Liège in Belgium, within a feasibility study.

The TICI will be the most innovative and sophisticated technology in the field of hearing solutions.

It **contains all the internal and external components of a cochlear implant system in one device placed underneath the skin**, including the audio processor, microphone and power supply.

A revolutionary milestone

With the first TICI implantation, MED-EL sets another revolutionary milestone in its long-standing history of technological innovations in the hearing implant field.

"It is our mission to overcome hearing loss as a barrier to communication and quality of life. For decades, our research and development has been based on close interdisciplinary collaboration with clinics and university departments. These collaborations allow us to continuously advance technology and solutions for people with a hearing loss. Developing a totally implantable device has been in the focus of MED-EL´s research for many years. I am very proud of our dedicated team of experts who have worked with creativity and diligence to develop this unique device within well over a decade.", says **Dr. Ingeborg Hochmair, founder and CEO of MED-EL**.

Prof. Dr. Philippe Lefèbvre, a leading expert in auditory implantology, **performing Europe's first in human TICI surgery**, points out: *"We tested the implant after surgery and are thrilled that everything is working as expected. Modern cochlear implant technology has been evolving at an impressive pace, delivering outstanding hearing results. The TICI is a milestone within the field of cochlear implantation. It has been a wish from the early days of cochlear implantation to be able to integrate all components within an internal device."*.

Learn more here.

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MED-EL – ideas4ears: MED-EL calls on children to unleash their superpowers to help people with hearing loss

The 4th edition of the ideas4ears children's invention contest was launched on World Inventors' Day, November 9th, 2020

The contest invites children aged 6-12 years to create an invention to improve the quality of life for people with hearing loss.

With the ideas4ears contest MED-EL celebrates children's creativity and aims to improve understanding of the challenges associated with hearing loss and deafness as well as the benefits of treatment.

How to participate

Parents interested should visit http://www.ideas4ears.org/enter and submit their child's entry until Sunday 17 January 2021, Kid Inventors' Day. Entries can be sent via a video, drawing, or sculpture. The most important factor is for young people to think big and channel their ideas to support those who cannot hear.

Win fabulous prizes!

The ideas4ears finalists and grand prize winners will be in the running to win educational resources to support their learning while home-schooling. There's a chance to win notebooks, tablets, and special prize packs.

All ideas are welcome, from the crazy to the conventional. Just remember: the inventions need to have the potential to help improve the lives of people with hearing loss at any age.

Raising Awareness for hearing loss challenges and treatments

ideas4ears was ranked among the top 100 business ideas of 2020 by El Mundo, Spain's second largest daily newspaper. The contest received the award in the Corporate Social Responsibility & Volunteering category, alongside high-profile names such as pharmaceutical giant Bristol Myers-Squibb and brewing company Heineken.

Learn more here.

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OTICON MEDICAL – Get online support today

Because of COVID-19, it is still difficult to get access to hearing care professionals for support in many countries. The need for online support has never been bigger. In the Support section on the Oticon Medical website you will find useful information to get the most out of your sound processor(s).

Do you need a quick repair and replacement service? Do you need to order batteries or to connect your sound processor to different connectivity solutions? Or do you need advice on going out to dinner or on how to communicate when wearing a mask with your sound processor?

In the Support section, you can find good advice for everyday life situations, hints and tips and all the necessary materials you need.
We are here to help you.

Get online support today

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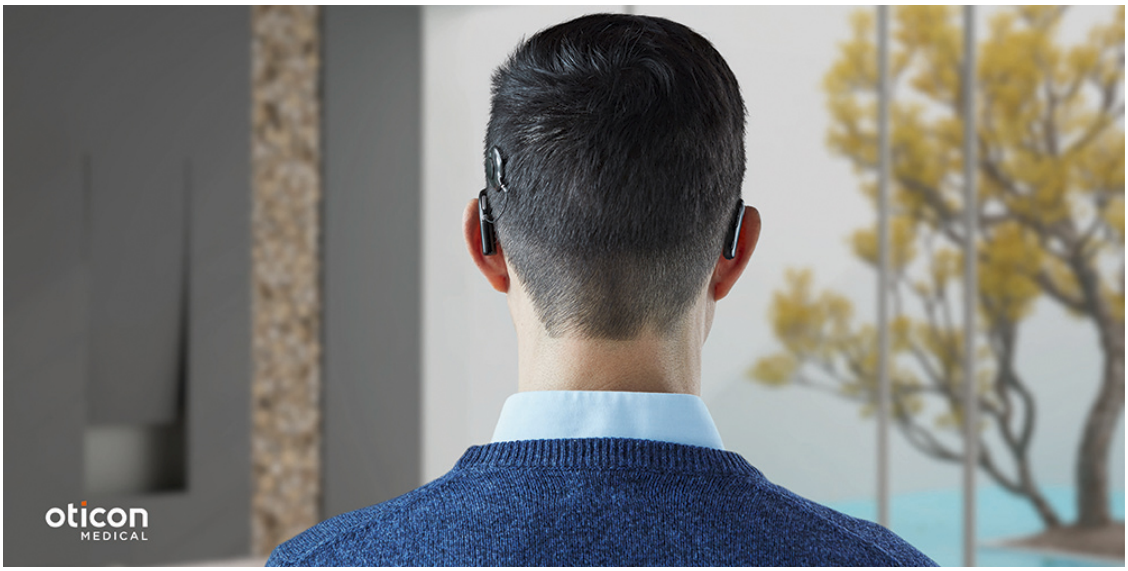
OTICON MEDICAL - Cochlear implant + hearing aid



The importance of hearing with both ears

For some people a cochlear implant on one ear and a hearing aid on the other ear could be an effective solution. This is known as a bimodal solution ***(1)***. Hearing with both ears is important as it helps speech understanding in noise and lets you know where sound is coming from.

Can two different hearing solutions complement each other?

The two solutions in a bimodal setup complement each other and together they may improve your overall hearing performance ***(2)***, ***(3)***. The cochlear implant provides clarity while the hearing aid provides loudness and sound depth.

If you have an Oticon Medical Neuro 2 cochlear implant, or are considering getting one, you may be able to support your hearing by combining your Neuro 2 with an Oticon hearing aid on the other ear. This gives you access to sound details on both sides, so it is easier to understand speech and localize sound.

Oticon and Oticon Medical are part of the Demant Group – one of the world's leading hearing healthcare companies and our devices are all designed to provide clean speech with minimal distortion using the principles of BrainHearing™. This recognizes that when it comes to listening, your brain is just as important as your ears and that your hearing devices need to support the brain to make sense of sound.

Bimodal solutions for Neuro 2 include Oticon Xceed – the world's most powerful hearing aid – and the well-established Oticon Dynamo. Whichever Oticon hearing aid you decide on, there are solutions available so you can wirelessly stream sound to both ears from your electronic devices.

Read more on Oticonmedical.com/bimodal.

(1) *Avan P, Giraudet F, Büki B. Importance of binaural hearing. Audiol Neurotol. 2015;20(suppl 1):3–6. DOI: 10.1159/000380741.*

(2) *Potts LG, Skinner MG, Litovsky RA, Strube MJ, Kuk F. Recognition and localization of speech by adult cochlear implant recipients wearing a digital hearing aid in the nonimplanted ear (bimodal hearing). J Am Acad Audiol. 2009;20(6):353–73. DOI: 10.3766/jaaa.20.6.4.*

(3) *Schafer EC, Amlani AM, Paiva D, Nozari L, Verret S. A meta-analysis to compare speech recognition in noise with bilateral cochlear implants and bimodal stimulation. Int J Audiol. 2011;50(12):871–80. DOI: 10.3109/14992027.2011.622300.*

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